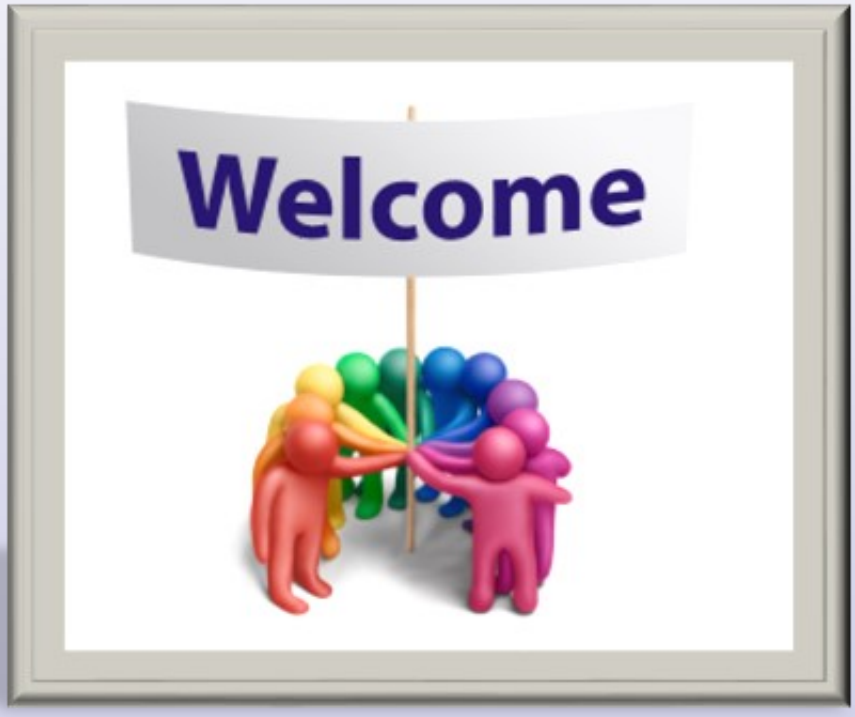
Nebraska Early Hearing Detection & Intervention Program

Advisory Committee Member Orientation Packet



Nebraska Department of Health & Human Services
Division of Public Health
http://dhhs.ne.gov/EHDI

NEBRASKA
Good Life. Great Mission.
DEPT. OF HEALTH AND HUMAN SERVICES
EARLY HEARING DETECTION & INTERVENTION PROGRAM

Rev 04/2021

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DEPT. OF HEALTH AND HUMAN SERVICES

EARLY HEARING DETECTION & INTERVENTION PROGRAM

Table of Contents:

History of EHDI:

How did EHDI start?

The concept of Newborn Hearing Screening stems back to 1967 with the National Conference on Education of the Deaf recommendations that testing of infants and children 5- 12 months of age should be investigated. However, it wasn't until 1988 that the issue was revisited. The Commission on Education of the Deaf reported the average age of identification for profoundly deaf children in the US was 2 1/2 years. An advisory group of national experts was selected by the U.S. Department of Education and Bureau of Maternal and Child Health to advise the government about the feasibility of developing early identification guidelines.

In 1993 the National Institutes of Health (NIH) Consensus Development Program recommended all newborns be screened for hearing loss before leaving the hospital. The Joint Commission on Infant Hearing (JCIH) documented their first Position Statement in 1994 recommending that "all infants with hearing loss should be identified before 3 months of age and receive intervention by 6 months of age."

In 1999 the American Academy of Pediatrics (AAP) endorsed Universal Newborn Hearing Screening with the goal of detecting hearing loss before three months of age and intervention services initiated by six months of age.

Congress passed the Newborn and Infant Hearing, Screening, and Intervention Act of 1999. This Act authorized funds and provided direction for the CDC to assist states in establishing infant hearing screening, evaluation, and intervention programs.

Nebraska's response to this Federal mandate was the Infant Hearing Act 2000, Statute LB 950. (page 6)

The following pages provide information on the History of the Joint Committee on Infant Hearing, the JCIH Position Statement, and the Nebraska Infant Hearing Act 2000.

Information taken from http://www.cdc.gov/ncbddd/hearingloss/ehdi- history.html

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EARLY HEARING DETECTION & INTERVENTION PROGRAM

Mission Statement

The Nebraska Early Hearing Detection and Intervention Program develops, promotes, and supports systems to ensure all newborns in Nebraska receive hearing screenings, family- centered evaluations, and early intervention as appropriate.

Information taken from http://www.cdc.gov/ncbddd/hearingloss/ehdi- goals.html

Introduction:

What is the purpose of EHDI?

EHDI (Early Hearing Detection and Intervention) is designed to identify infants who are deaf or hard of hearing by Universal Newborn Hearing Screening (UNHS). The early identification process allows identified infants to be enrolled in early intervention programs as soon as possible. The vision of the CDC EHDI program is to promote communication from birth for all children.

The mission of EHDI is for every state and territory to have a complete EHDI data system that will help ensure children who are deaf or hard of hearing achieve communication and social skills commensurate with their cognitive abilities.

EHDI programs are implemented at the state level with collaboration and support from federal, state, and private organizations. The EHDI process is characterized by three main components: screening, audiologic evaluation, and early intervention.

Data compiled by the CDC is used to help states improve and strengthen their EHDI program and data management systems. It is also used to help states and families ensure that infants are identified as soon as possible, and the infants' language, cognitive skills and academic abilities are supported through early intervention services.

CDC

History of the

Joint Committee on Infant Hearing

The Joint Committee on Infant Hearing (JCIH) was established in late 1969 and composed of representatives from audiology, otolaryngology, pediatrics, and nursing. It was the American Speech Language Hearing Association (ASHA), the then American Academy of Ophthalmology and Otolaryngology (AAOO) and the American Academy of Pediatrics (AAP) who first met. The Committee was charged with a two- fold responsibility: first, to make recommendations concerning the early identification of children with, or at- risk for hearing loss and second, newborn hearing screening. In 1970, the Committee's first statement was that mass hearing screening could not be justified at that time because there were no appropriate test procedures. The statement encouraged ongoing research and acknowledged the need to detect hearing loss early in life.

Throughout its over 30- year history, the Committee explored the complexities of hearing loss and its effect on a child's development, seeking to find newer and better methods to identify and serve the infants and their families. Today, the Joint Committee is composed of representatives from the American Academy of Pediatrics, the American Academy of Otolaryngology and Head and Neck Surgery, the American Speech Language Hearing Association, the American Academy of Audiology, the Council on Education of the Deaf, and Directors of Speech and Hearing Programs in State Health and Welfare Agencies.

The Committee's primary activity has been publication of position statements summarizing the state of the science and art in infant hearing, and recommending the preferred practice in early identification and appropriate intervention of newborns and infants at risk for or with hearing loss. A 1972 statement delineated the first high- risk factors for hearing loss and recommended following infants with these high risk factors: history of hereditary childhood hearing impairment, congenital perinatal infection such as rubella or other nonbacterial fetal infection like cytomegalovirus, and herpes; craniofacial anomalies, birth weight less than 1500 grams and a bilirubin level greater than 20. In 1982, bacterial meningitis and severe asphyxia were added. Additional risk indicators were added between 1982 and 1994. Each statement has become more explicit in its recommendations for detecting and monitoring infants with suspected hearing loss.

In 1994, the JCIH endorsed universal detection of hearing loss in newborns and infants and stated that all infants with hearing loss

Information taken from jcih.org

be identified before 3 months of age and receive intervention by 6 months. To gain access to most infants, the JCIH recommended evaluation prior to hospital discharge. Through the 1994 Position Statement, the JCIH supported and clarified the National Institute of Healthcare (NIH) Position Statement in an effort to move our common agenda forward.

Following publication of the 1994 statement, the JCIH Committee members recognized the importance of stakeholder input if members were to understand what was needed next. The first JCIH stakeholders meeting was held in Dallas in 1995. Proceedings were published in the American Journal of Audiology and provided Committee members with the critical issues that needed addressing if early detection was to become a successful reality. Committee members acknowledged that poorly designed and managed programs would prove detrimental to early identification efforts. In 1999, Pediatric Clinics of North America published an issue on early hearing loss with all chapters written by current and former Committee members. That issue was the precursor to the comprehensive and widely peer- reviewed 2000 position statement.

JCIH 2000 recommends universal screening of hearing loss before hospital discharge and identifies Principles and Guidelines for hospital and state level programs. The 2000 statement promotes a system as essential for the detection and intervention of early hearing loss. That system is composed of screening before hospital discharge, follow- up and diagnosis for infants needing additional care and the intervention and habilitation for infants identified with hearing loss. (Figure 1: Three Component of Early Hearing Detection and Intervention Programs). In 2000, the focus is on quality and assuring that each infant receives the care she needs. The JCIH continues its efforts to promote quality in early hearing detection. In 2001, a second stakeholder conference was held in Rockville Pike, Maryland. The goal of that meeting was again for Committee to learn about needed next steps.

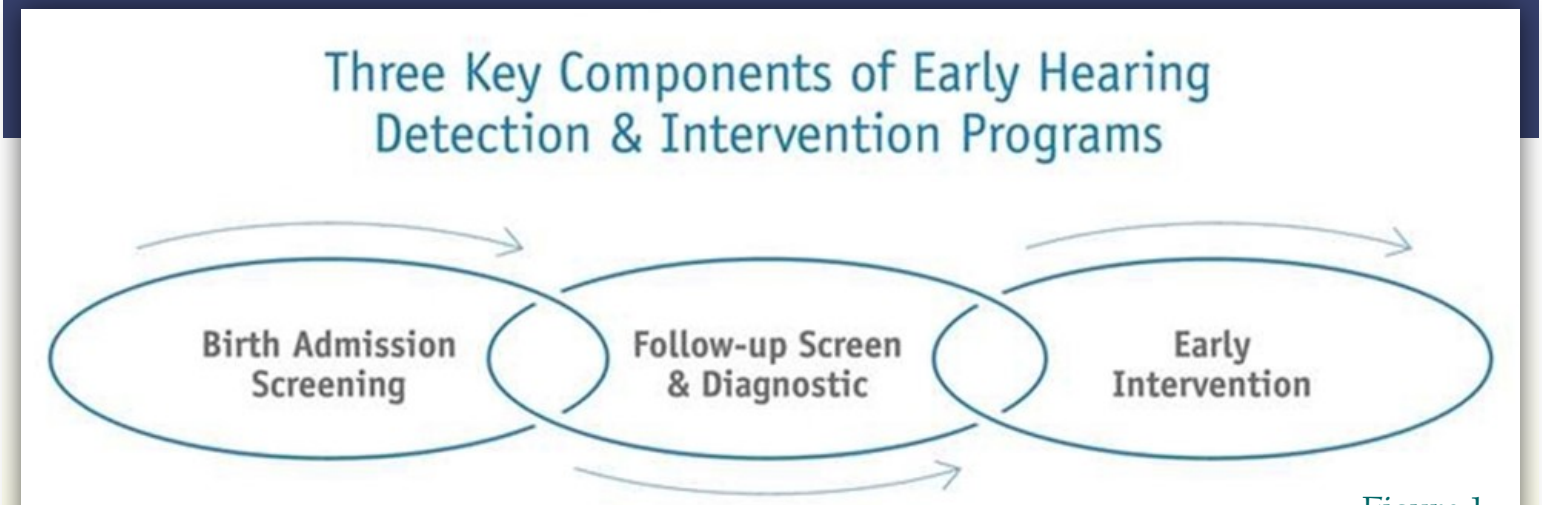


Figure 1

JCIH 1-3-6 Goals

The Joint Committee on Infant Hearing has established 1-3-6 goals for newborn hearing screening and follow-up.

All infants should receive a hearing screening by ***one*** month of age.

All infants who refer should receive a diagnostic evaluation prior to ***three*** months of age.

All infants who are identified as deaf or hard of hearing should begin receiving early intervention services by ***six*** months of age.

Taken From:

The American Academy of Pediatrics JCIH Year 2019 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs

Joint Committee on Infant Hearing Position Statement

The Joint Committee on Infant Hearing (JCIH) endorses early detection of and intervention for infants with hearing loss. The goal of early hearing detection and intervention (EHDI) is to maximize linguistic competence and literacy development for children who are deaf or hard of hearing. Without appropriate opportunities to learn language, these children will fall behind their hearing peers in communication, cognition, reading, and social- emotional development. Such delays may result in lower educational and employment levels in adulthood. To maximize the outcome for infants who are deaf or hard of hearing, the hearing of all infants should be screened at no later than 1 month of age. Those who do not pass screening should have a comprehensive audiological evaluation at no later than 3 months of age. Infants with confirmed hearing loss should receive appropriate intervention at no later than 6 months of age from health care and education professionals with expertise in hearing loss and deafness in infants and young children. Regardless of previous hearing- screening outcomes, all infants with or without risk factors should receive ongoing surveillance of communicative development beginning at 2 months of age during well-child visits in the medical home. EHDI systems should guarantee seamless transitions for infants and their families through this process.

To read the full JCIH *Position Statement 2019* and the *Supplement to the JCIH 20019Position Statement: Principles and Guidelines for Early Intervention* visit jcih.org

Nebraska Newborn Hearing Screening Law

Neb. Rev. Stat. § 71- 4734 et seq. (2000) create the Infant Hearing Act, which requires the department of health and human services to implement a system that tracks newborns identified with a hearing loss. The law requires every birthing facility to educate the parents of newborns on the importance of receiving a hearing screening test and necessary follow- up care. The law also requires that by December 1, 2003, each birthing facility include a hearing screening test as part of its standard of care for newborns and establish a mechanism for compliance review. The law specifies that a hearing screening test shall be conducted on no fewer than 95 percent of the newborns born in the state. The law requires payment for hearing screening tests to be covered under medical assistance and health insurance plans.

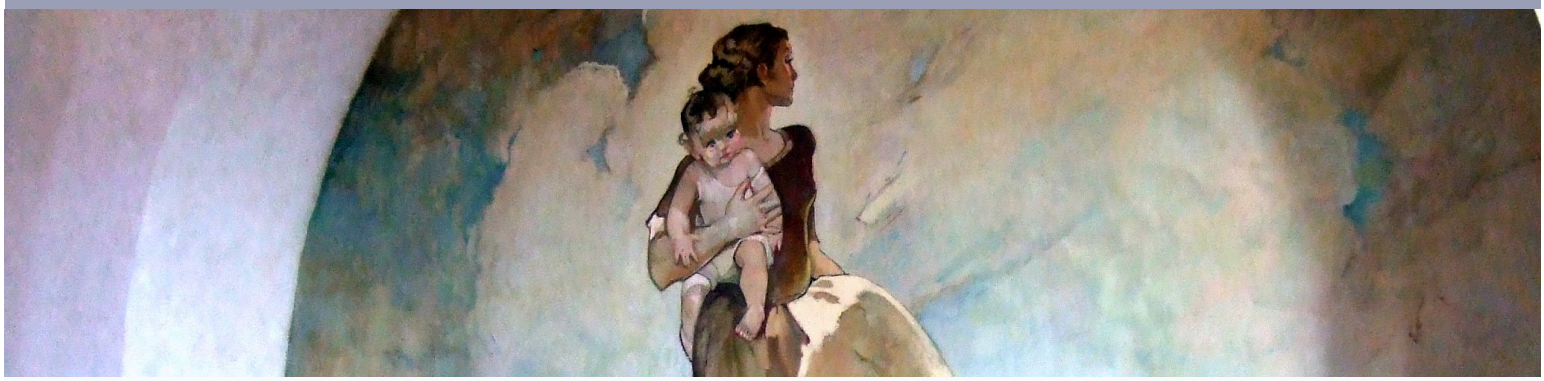
With Early Intervention in mind, states have taken action to ensure that children are screened early. Nebraska's response was to create the Infant Hearing Act in 2000.

Information taken from: http://www.ncsl.org/research/health/newborn-hearing- screening- state-laws.aspx

Nebraska Summary of Universal Newborn Hearing Screening Legislation

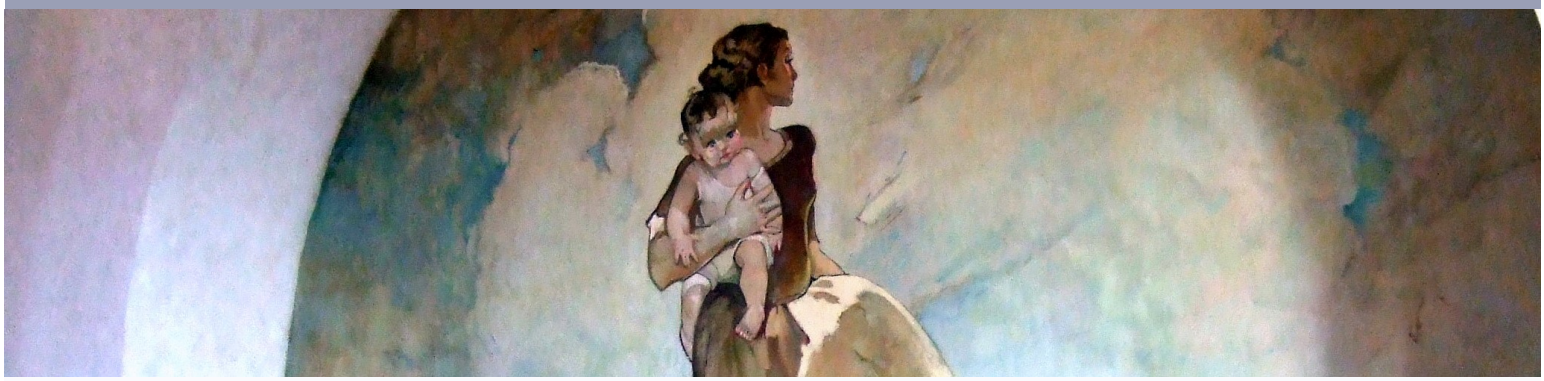
Excerpts from Legislation/Rules & Regulations		
Year Passed	**2000**	LB 950 (2000)
Full implementation by:	**12/01/2003**	Statute: 71- 4742. (1) By December 1, 2003, each birthing facility shall include a hearing screening test as part of its standard of care for newborns and shall establish a mechanism for compliance review. By December 1, 2003, a hearing screening test shall be conducted on no fewer than ninety- five percent of the newborns born in this state.
Requires Screening of	**›95%**	Statute: 71- 4742. (1) By December 1, 2003, each birthing facility shall include a hearing screening test as part of its standard of care for newborns and shall establish a mechanism for compliance review. By December 1, 2003, a hearing screening test shall be conducted on no fewer than ninety- five percent of the newborns born in this state. (2) If the number of newborns receiving a hearing screening test does not equal or exceed ninety- five percent of the total number of newborns born in this state on or before December 1, 2003, or falls below ninety - five percent at any time thereafter, the Department of Health and Human Services shall immediately adopt and promulgate rules and regulations implementing a hearing screening program. The hearing screening program shall provide for a hearing screening test that every newborn born in this state shall undergo and shall provide that the hearing screening test be completed during birth admission or, if that is not possible, no later than three months after birth. Notwithstanding this section, it is the goal of this state to achieve a one hundred- percent screening rate. Source: LB950, 2000

Excerpts from Legislation/Rules & Regulations (continued)		
Covered Benefit of Health Insurance?		**Statute:** 44- 796. Coverage for certain hearing screening tests; requirements. (1) Notwithstanding section 44- 3, 131: (a) Under a health insurance plan which provides coverage for hearing screening tests for newborns and infants, such coverage shall be subject to copayment, coinsurance, deductible, and dollar- limit provisions to the extent that other medical services covered by the health insurance plan are subject to such provisions; and (b) This sections applies to health insurance plans delivered, issued for delivery, or which become effective on or after April 11, 2000, and also applies to all renewals or changes which are effective on or after April 11, 2000. (2) For purposes of this section, health insurance plan means a plan which includes dependent coverage for children which is delivered, issued for delivery, renewed, extended, or modified in this state. A health insurance plan includes any such group or individual sickness and accident insurance policy, health maintenance organization contract, subscriber contract, employee medical, surgical, or hospital care benefit plan, or self- funded employee benefit plan to the extent not preempted by federal law. Health insurance plan does not include policies providing coverage for a specific disease, accident- only coverage, hospital indemnity coverage, disability income coverage, Medicare supplement coverage, long- term care coverage, or other limited- benefit coverage. (3) The Department of Insurance shall adopt and promulgate rules and regulations necessary to implement this section. *Source:* Laws 2000, LB 950 **Statute:** 68- 1019.06. Hearing screening tests for newborns and infants; how paid. (1) The Department of Health and Human Services Finance and Support shall provide payment for hearing screening tests for newborns and infants through the medical assistance program if the child is eligible for medical assistance as determined by state and federal law. (2) Any contract for the provision of medical assistance negotiated with a managed care organization shall include payment for hearing screening tests for newborns and infants.



Nebraska Summary of Universal Newborn Hearing Screening Legislation

Excerpts from Legislation/Rules & Regulations (continued)		
Report to State Department of Health	Yes	Statute: 71- 4739. Birthing facility; confirmatory testing facility; reports required. (1) Beginning December 1, 2000, and annually thereafter, every birthing facility shall report to the Department of Health and Human Services the number of: (a) Newborns born; (b) Newborns and infants recommended for a hearing screening test; (c) Newborns who received a hearing screening test during birth admission; (d) Newborns who passed a hearing screening test during birth admission if administered; (e) Newborns who did not pass a hearing screening test during birth admission if administered; and (f) Newborns recommended for monitoring, intervention, and follow- up care. (2) Beginning December 1, 2000, and annually thereafter, every confirmatory testing facility shall report to the Department of Health and Human Services the number of: (a) Newborns and infants who return for a follow- up hearing test; (b) Newborns and infants who do not have a hearing loss based upon the follow- up hearing test; and. (c) Newborns and infants who are shown to have a hearing loss based upon the follow- up hearing test. Source: LB950, 2000



Nebraska Summary of Universal Newborn Hearing Screening Legislation

Excerpts from Legislation/Rules & Regulations (continued)		
Provision of Educational Materials	Yes	Statute: 71- 4740. Hearing loss educational information. (1) Beginning January 1, 2001, every birthing facility shall educate the parents of newborns born in such facilities of the importance of receiving a hearing screening test and any necessary follow- up care. This educational information shall explain, in lay terms, the hearing screening test, the likelihood of the newborn having a hearing loss, follow- up procedures, and community resources, including referral for early intervention services under the Early Intervention Act. The educational information shall also include a description of the, normal auditory, speech, and language developmental process in children. Education shall not be considered a substitute for the hearing screening test. (2) If a newborn is not born in a birthing facility, the Department of Health and Human Services shall educate the parents of such newborns of the importance of receiving a hearing screening test and any necessary follow- up care. The department shall also give parents information to assist them in having the test performed within three months after the date of the child's birth. Source: LB950, 2000

To read the Rules & Regulations in full, please visit http://www.infanthearing.org/legislative/legislation/nebraska2000_lb950.html

Funding Sources

The NE-EHDI Program receives funding from the HRSA EHDI, the HRSA Title V Block Grant, and the CDC. The HRSA EHDI grant funds the basic operations of the program. The CDC cooperative agreement primarily funds the development, implementation, maintenance, and expansion of the integrated electronic data reporting and tracking system (ERS-II). The HRSA Title V Block Grant helps fund basic operations of the EHDI program when there isn't enough funding from the other sources and/or isn't allowed in the other funding sources.

HRSA Maternal & Child Health

Title V of the federal Social Security Act is designed to improve the health of mothers and children by investing in programs that enable mothers to give birth to healthy babies and that promote the health of children and adolescents, including children and youth with special health care needs.

HRSA is an agency of the U.S. Department of Health and Human Services and is the primary Federal agency for improving access to health care services for people who are uninsured, isolated, or medically vulnerable.

The HRSA grant has six system goals or aims:

1) Lead efforts to engage all EHDI system stakeholders at the state/territory level to improve developmental outcomes of children who are DHH;
2) Provide a coordinated infrastructure to:
   - Ensure that newborns are screened by 1 month of age, diagnosed by 3 months of age, and enrolled in EI by 6 months of age (1-3-6 recommendations); and
   - Reduce loss to follow-up/loss to documentation.
3) Identify ways to expand state/territory capacity to support hearing screening in young children up to 3 years of age;
4) Strengthen capacity to provide family support and engage families with children who are DHH and adults who are DHH throughout the EHDI system;
5) Engage, educate, and train health professionals and service providers in the EHDI system about the 1-3-6 recommendations; the need for hearing screening up to age 3, the benefits of a family-centered medical home and the importance of communicating accurate, comprehensive, up-to-date, evidence-based information to families to facilitate the decision-making process; and
6) Facilitate improved coordination of care and services for children who are DHH and their families through the development of mechanisms for formal communication, training, referrals, and/or data sharing between the state/territory EHDI Program and the Individuals with Disabilities Education Act (IDEA) Program for Infants and Toddlers with Disabilities (Part C) Program.

The CDC (Center for Disease Control) is a federal agency under the Department of Health and Human Services whose main goal is to protect public health and safety through the control and prevention of disease, injury, and disability.

The CDC cooperative agreement has eight main goals:

1) Document unduplicated, individually identifiable data on the delivery of newborn hearing screening services for all infants born in the jurisdiction.
2) Support tracking and documentation of the delivery of follow- up services for every infant/child who did not receive, complete or pass the newborn hearing screening.
3) Document all cases of hearing loss, including congenital, late- onset, progressive, and acquired cases for infants/children <3 years old.
4) Document the enrollment status, delivery and outcome of early intervention services for infants and children <3 years old with hearing loss.
5) Maintain data quality (accurate, complete, timely data) of individual newborn hearing screening, follow- up screening and diagnosis, early intervention and demographic information in the EHDI- IS.
6) Preserve the integrity, security, availability and privacy of all personally-identifiable health and demographic data in the EHDI- IS.
7) Enable evaluation and data analysis activities.
8) Support dissemination of EHDI information to authorized stakeholders.

Staff

Program Manager - Brenda Coufal, BS (Full Time)

Brenda has been with the NE- EHDI Program since August 2016 and is responsible for managing grant and program activities, including preparation of budgets and reports, project management, staff supervision and management and administration of contracts.

Business Analyst – Jim Beavers, BGS (Full Time, Contracted)

Jim has been with the NE- EHDI Program since June 2006 and is responsible for data management and reporting, system maintenance and enhancements and user support.

Community Health Educator Sr. – MeLissa Butler, BS (Full Time)

MeLissa has been with the NE- EHDI Program since April 2011 and is responsible for all activities related to conducting follow- up to assure appropriate hearing screening, diagnosis, referral and intervention for infants who do not pass the newborn hearing screening.

Family Support Coordinator– Shelli Janning (Part Time, Contracted)

Shelli has been with the NE-EHDI Program since May 2017 and is responsible for following up on babies in all stages of the hearing screening protocol, and contacting parents to ensure they are connected with the appropriate resources and family support.

Community Health Educator – Bailey Heaton, BS, Audiology Intern, UNL (Part Time)

Bailey has been with the NE- EHDI Program since March 2020 and is responsible for following up on identified babies, contacting parents to ensure they follow through with the needed testing, and are connected with the appropriate resources.

Nebraska Early Hearing Detection and Intervention Program

Advisory Committee Charter

MISSION:

The Nebraska Early Hearing Detection and Intervention Program develops, promotes, and supports systems to ensure all newborns in Nebraska receive hearing screenings, family- centered evaluations, and early intervention as appropriate.

PURPOSE:

The purpose of the Nebraska Early Hearing Detection and Intervention (NE- EHDI) Advisory Committee is to provide direction and guidance to the NE- EHDI Program regarding the newborn hearing screening system. Specific Advisory Committee activities include, but are not limited to, the following:

- To discuss and advise on the goals for the NE- EHDI Program.
- To advise on the improvement of reporting, tracking, and follow- up protocols to effectively link the NE- EHDI Program and the early intervention systems.
- To assist in increasing the Program's responsiveness to the expanding cultural and linguistic communities in the state.
- To guide the long- term planning and evaluation of the NE- EHDI system in the state.
- To review the bi- annual newborn screening statistics and make recommendations for program improvements.

MEMBERSHIP:

The membership of the Advisory Committee shall be culturally and geographically representative of stakeholders with an interest in and concern for newborn hearing screening. The Advisory Committee shall consist of not more than 30 voting members and the NE- EHDI Program Manager who is a non- voting member. Membership will include representatives from the following areas:

- Audiology
- Deaf/Hard of Hearing Community
- Early Intervention Services (e.g. teacher, Speech- Language Pathologist) & Early Intervention Coordination
- Ears, Nose and Throat Specialist/Otorhinolaryngologists or Otologist
- Family Support
- Hospitals (preferably hearing screening coordinator)
- Parents
- Pediatrics
- Public Health

Advisory Committee Charter (con't)

Each member is requested to serve a term of two years but may continue to serve at their discretion for longer periods, unless their absence at meetings exceeds attendance.

Specifically, any member who does not attend at least one meeting per year for two years in a row will be removed from the Advisory Committee. Terms for existing members will begin at the first of the year, or as positions vacate.

The terms of the Chair and Vice- Chair will be four years. Their terms will begin at the first meeting of the calendar year. Nominations for chair and vice char will be made at the last Advisory Committee meeting of the term.

The Chair, and in the absence of the Chair, the Vice- Chair will be responsible for the following:

- Leading the Advisory Committee meetings with the NE- EHDI Program Manager.
- Approval of meeting agendas and minutes.
- Representing (or designate) the Advisory Committee as appropriate.
- Chair may call a meeting of the Advisory Committee at their discretion.

Advisory Board Vacancies: Vacancies will be filled within six months. Terms will begin when the vacancy is filled. The Program Manager will work with the Chair and other Advisory Committee members to identify new members.

Officer Vacancies: If the Chair resigns, the Vice- Chair will finish the term of the Chair. The Committee will nominate and vote on a new Chair- Elect. If the Chair- Elect resigns, the Committee will nominate and vote on a new Chair- Elect.

MEETINGS:

The Advisory Committee will meet bi- annually as needed. A member who is unable to attend may send a non- voting representative. The Chair may call for emergency/interim meetings at his/her discretion.

The Advisory Committee will generally make its recommendations by consensus. In the event that consensus cannot be reached within a reasonable timeframe, there will be a majority rule, as in a simple majority of those present or more than 50 percent. However, at least 50 percent of the members must be present.

CHARTER CHANGES:

This Charter may be amended, altered, or repealed, and a new one adopted by a majority vote of the Advisory Board membership.

Amended Charter approved by the committee 05/09/2019

Stakeholders

The Nebraska Early Hearing Detection and Intervention Program Charter states the following concerning membership:

"The membership of the Advisory Committee shall be culturally and geographically representative of stakeholders with an interest in and concern for newborn hearing screening. The Advisory Committee shall consist of not more than 30 voting members and the NE- EHDI Program Manager who is a non- voting member. Membership will include representatives from the following areas"

Advisory Committee Representation

Audiology:

- Laura Beshaler, Au.D., CCC- A - Millard Public Schools
- Kirstin Jolkowski, Au.D., CCC- A - LPS
- Ashley Kaufman, Au.D., CCC- A - Boys Town
- Stacie Ray, Au.D., CCC- A - UNL Barkley (Parent)
- Merry Spratford Au.D., CCC-A - Boys Town
- Joanna Webster Au.D.,CCC-A - Children's Hospital

Deaf/Hard of Hearing Community:

- Mark Anderson - NeAD
- Linsay Darnall, Jr.
- Jayden Jensen
- Jessica Larrison - NCDHH
- Anne Thomas - UNL Dept. of SPED & Communication Disorders

Early Intervention Services & Coordination:

- Jessica Anthony - EDN, DHHS
- Katie Brennan, MS, CCC- SLP - UNL Barkley
- Amy Bunnell - EDN, NDE
- Brad Czaplewski - ESU 10
- Sue Czaplewski - ESU 9, NDE
- Cole Johnson - NDE, SPED
- Joan Luebbers - NDE, Head Start
- Sara Peterson - ESU 13

Ears, Nose and Throat Specialist/Otorhinolaryngologists or Otologist, EHDI Chapter Champion:

- Heather Gomes, MD - Boys Town

Family Support:

- Nina Baker- PTI Nebraska
- Shelli Janning - Nebraska Hands & Voices, Guide By Your Side (Parent)

Hospitals:

- Carlena Conard, RN, BSN - York General Hospital

Parents:

- Jessica Hoss
- Kelly Rausch
- Colleen Richart
- Jana Wiblishouser

Pediatrics:

- Pam Zegers, MD- Complete Children's Health

Public Health:

- Karen Rolf, Ph.D. - UNO

Advisory Committee Member Roster

Mark Andersen Nebraska Association of the Deaf 19022 B Street Omaha, NE 68130 cheekers3365@yahoo.com	**Heather Gomes, MD** (CHAPTER CHAMPION) Boys Town Otolaryngologist 555 N 30th St Omaha NE 68131 Heather.Gomes@boystown.org	**Kelly Rausch** Parent/Advocate Advisor KJRausch@hotmail.com
Jessica Anthony Early Development Network Nebraska Dept. of Health & Human Services P.O. Box 95026 Lincoln, NE 68509 Jessica.Anthony@nebraska.gov	**Jessica Hoss** Nebraska Hands & Voices/Guide By Your Side Parent Guide JessicaSueHoss@gmail.com	**Stacie Ray, Au.D., CCC-A (CHAIR)** Parent/Barkley Center for Communications, UNL 253 Barkley Memorial Center Lincoln NE 68583-0731 Stacie.Ray@unl.edu
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Sue Czaplewski Nebraska Department of Education- ESU#9 1117 East South St. Hastings NE 68901 Sue.Czaplewski@esu9.us	**Joan Luebbers** Head Start State Collaboration Office Nebraska Department of Education 301 Centennial Mall South Lincoln, NE 68509 Joan.Luebbers@nebraska.gov	**Pam Zegers, MD** Complete Children's Health 3901 Pine Lake Road Lincoln, NE 68516 Pam.Zegers@cch-neb.com
Linsay Darnall, Jr Deaf Advocate/Advisor PO Box 66 Polk NE 68654 LDarnallJr@hotmail.com	**Sara Peterson** Teacher of the Deaf, ESU #13 4215 Avenue I Scottsbluff NE 69361 SPeterson@esu13.org	**OPEN**

Deaf Community Representation

"Deaf professionals and deaf community organizations should be integral parts of Early Hearing Detection and Intervention (EHDI) systems. Individuals who have grown up deaf or hard of hearing are in a unique position to provide information and support to families with young deaf or hard- of- hearing children."

"Research shows that contact with the deaf community helps families transition to acceptance of their child as a deaf person. Deaf Community members are able to provide the deaf child with something hearing parents cannot: Experience as a deaf person."

"Parents have the right to be informed of all resources and opportunities that can assist them in raising their child. The deaf and hard- of- hearing community is key in this category of resources."

Involving the Deaf Community in EHDI systems can help move these systems from using a purely medical approach to employing a socio- cultural model. While the medical model sees deaf children as having a loss or deficit, the socio- cultural model focuses on the connections the child has in his or her environment, including the family. The table below demonstrates the differences in these two approaches through the use of terminology.

Medical Model vs. Socio- Cultural Model

MEDICAL MODEL	SOCIO- CULTURAL MODEL
Communication options	Communication opportunities
Hearing loss	Hearing level, status, abilities, or differences
Intervention	Involvement or identification
Failed hearing test	Refer with explanation
Diagnosis	Identification
Fix the ear	Modify or cope
Deafness	Deaf, deaf people, being deaf
Hearing impaired	Deaf or hard of hearing
Vocationally limited	Unlimited opportunities
Grief process	Journey
Disability (cannot)	Cultural (adapt)
Auditory technology	Visual and auditory technology

Information taken from the NCHAM eBook, A Resource Guide for Early Hearing Detection & Intervention, Chapter 20, *Deaf Community Support for Families: The Best of Partnerships*, pages 2 & 3.

Communication Tips

Communicating With a Diverse Group

The following tips are provided to enhance communication with individuals who are deaf or hard of hearing. Often very minor adjustments by the person speaking will greatly increase the ability of the listener to understand what is being said. These tips can even help communication among individuals with normal hearing.

- Always speak clearly and naturally.
- For older individuals, you may need to speak slower. Shouting can cause distortion of hearing aids and often makes the words even more unintelligible. Speak slowly enough that the words can be distinguished from one another.
- Use different words if you are misunderstood. Certain sounds may cause the listener difficulty. If you need to repeat you sentence, try to use different words that may be easier to understand.
- Not all individual who are deaf or hard of hearing can read lips, but for those who can, here are a few tips to make it easier for them to communicate. Face the listener. Do not hide your mouth or chew while talking. Also try to have the room lighted to prevent shadows. Keep at eye level with them.
- Attract their attention BEFORE you begin. Be sure the listener knows that you are trying to communicate with them before you begin. You can say their name or lightly touch them to get their attention.
- Stay close to the listener. If the listener can hear better on one side, try to stay on that side if possible. Also do not attempt to talk to someone if you are in a different room or if there are other distracting noises. Always try to remain within 3- 5 feet of the listener.
- Turn off or decrease other room noise. Other noises can mask or block speech. Televisions, radios, even other people talking can greatly affect the ability to discriminate speech. For example, you can request a quiet corner in a restaurant or go at a less busy time. Reduce the background noise as much as possible before beginning the conversation.
- Use facial expressions and hand gestures to emphasize your feelings. This will help the listener understand your emotions and thereby help them understand more what you are trying to communicate.
- If all these efforts fail, write down your key points.

For more information: www.ncdhh.ne.gov

Definitions & Terms

Definitions

1- 3- 6	The optimal number of months recommended by JCIH and EHDI for screening, identification, and early intervention services to take place. Initial hearing screening should occur by one month of age; identification should occur by three months of age; enrollment in early intervention services should occur by six months of age.
Diagnostic Evaluation	Comprehensive examination of hearing to determine hearing ability and, if so, the type, degree, and configuration.
Early Hearing Detection and Intervention (EHDI) Program	Program designed to identify newborns who are deaf or hard of hearing by universal newborn hearing screening and to enroll identified newborns in early intervention programs.
Medical Home	A patient- centered medical home is a health care delivery model in which a patient establishes an ongoing relationship with a physician in a physician- directed team, to provide comprehensive, accessible, family centered, culturally competent and continuous primary and preventive care, and to coordinate the patient's health care needs across the health care system in order to improve quality, safety, access, and health outcomes in a cost effective manner.
Newborns	Infants from birth to 30 days of age; for purposes of this document, those undergoing newborn hearing screening, even if they are older than 30 days.
Newborn Hearing Screening (NBHS)	Screening conducted in the newborn period. The primary purpose of newborn hearing screening is to identify newborns who are likely to be deaf or hard of hearing and who require further evaluation. A secondary objective is to identify newborns with medical conditions that can lead to becoming deaf or hard of hearing and to establish a plan for ongoing monitoring of their hearing status.
Pass	Screening result for both ears that meets or exceeds set criteria and requires no follow- up, unless risk indicators for late- onset or changes in hearing ability exist.
Permanent Childhood Hearing Loss (PCHL)	All permanent bilateral or unilateral conductive, sensory, neural or mixed types of hearing loss.
Refer	Screening results that indicate a possibility that an infant is deaf or hard of hearing and requires a re- screening or diagnostic evaluation.
Screening	Examination of seemingly asymptomatic persons to determine if they are likely or unlikely to exhibit the condition of interest.

Definitions & Terms

Terms used to indicate a baby's follow- up status

Closed	Baby has passed a hearing screening or diagnostic evaluation in both ears.
Diagnosed	Baby has been identified as deaf or hard of hearing.
Expired	Baby has passed away.
Follow- 1	Follow- up is ongoing due to baby referring on an outpatient screening with no indication of middle ear involvement.
Follow- 2	Follow- up is ongoing due to baby referring on an outpatient screening with indication of middle ear involvement.
Lost	An infant greater than six months of age who did not pass their newborn hearing screening and the status of follow- up testing is unknown. Could be categorized as Lost to Follow- up, Lost to System or Lost to Documentation.
Monitor	Hearing screening results for both ears meets set criteria for normal hearing, but risk factors for late onset hearing loss are indicated.
Moved	Baby who was born in Nebraska but has moved out of the state.
Open	Baby with an active hearing information record with no inpatient results reported yet.
Other	Follow- up is not ongoing for reasons such as baby was born at home, baby is in the NICU or transferred to another hospital after birth.
Other- homebirth	Baby was born outside of the hospital either planned or unplanned.
Refused	Parents refused the hearing screening, either inpatient or outpatient.
Unresponsive	A documented two- way conversation or written communication with the child's legal parent or guardian in which they have acknowledged awareness of the corresponding 1:3:6 recommendation and have nevertheless not obtained the recommended service.
Working	Follow- up is ongoing due to baby referring on the inpatient screening or being discharged from the hospital without a hearing screening.

Communication Approaches

Definitions of Communication Approaches & Opportunities

American Sign Language (ASL)

"ASL is a complete, complex language that employs signs made by moving the hands combined with facial expressions and postures of the body. It is the primary language of many North Americans who are deaf and is one of several communication options used by people who are deaf or hard- of- hearing."*

American Sign Language/English Bilingual Bimodal

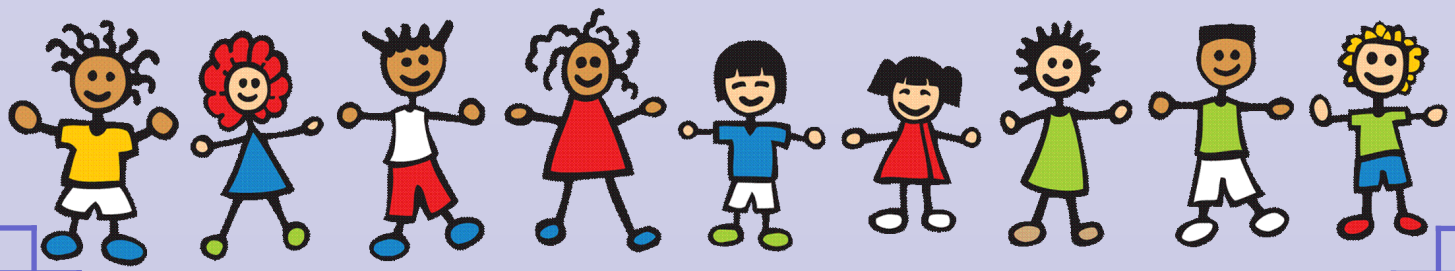
This approach "supports the acquisition, development and use of American Sign Language and English. The goal is for each child to develop linguistic proficiency in ASL and written English. Spoken English is a component of this approach. It is valued, encouraged, and incorporated and is specific to an individual child's characteristics and goals. Each language is kept separate but whole. Each language is used when it is accessible and meaningful."**

Auditory- Oral

"This approach encourages children to make use of the hearing they have (called *residual hearing*) using hearing aids or cochlear implants. Speechreading, sometimes called lipreading, is used to supplement what's detected through residual hearing. In this approach, children learn to listen and speak but do not learn sign language."***

Auditory-Verbal

"A key element of this approach is teaching children to make effective use of their residual hearing – either via hearing aids or a cochlear implant. Therapists work one- on - one with the child to teach him or her to rely only on listening skills. Because parent involvement is an important part of the auditory- verbal approach, therapists also partner with parents and caregivers to provide them with the skills they need to help the child become an auditory communicator. In this approach, neither speechreading nor the use of sign language is taught."***



Communication Approaches

Definitions of Communication Approaches & Opportunities

Cued Speech

"In this system, children learn to both "see" and "hear" spoken language. They focus on the movements that the mouth makes when we talk. This is combined with: (a) eight hand shapes (called *cues*) indicating groups of consonants, and (b) four positions around the face, indicating vowel sounds. Some sounds look alike on the lips – such as "b" and "p" – and others can't be seen on the lips – such as "k". The hand cues help the child tell what sounds are being voiced."***

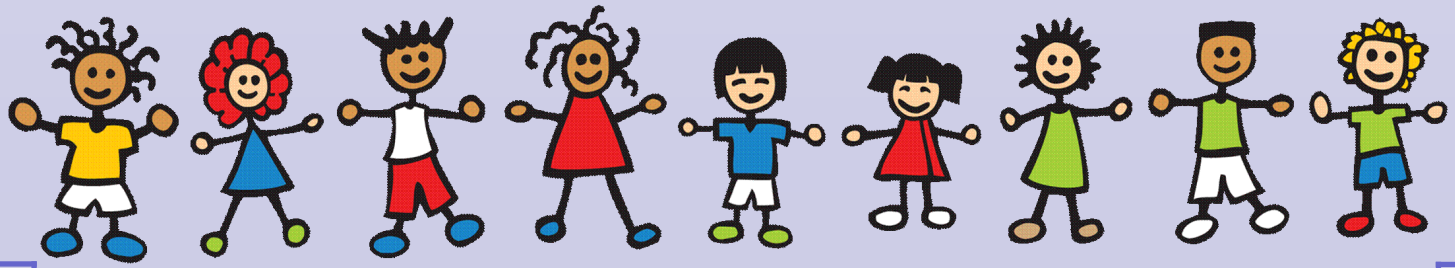
Signed Exact English (SEE)

"SEE is a sign communication system that represents literal English. It is a tool to make visible everything that is not heard. SEE modifies and supplements the vocabulary of American Sign Language (ASL) so children can see clearly what is said in English." ****

Total Communication

"In this communication system, methods are combined. Children learn a form of sign communication. They also use finger spelling, speechreading, speaking, and either hearing aids or cochlear implants."***

*Information taken from www.nidcd.nih.gov/health/hearing/pages/asl
**Information taken from "Everything You Always Wanted to Know About ASL/ English Bimodal Bilingual Education" from www.gallaudet.edu/Documents/Clerc/ Handout
***Information taken from *Opening Doors: Technology and Communication Options for Children with Hearing Loss*, printed by the U.S. Department of Education, 2006
****Information taken from www.seecenter.org



Acronyms & Abbreviations

AAP	American Academy of Pediatrics	MHCP	Medically Handicapped Children's Program
ABR	Auditory brainstem response	NAD	National Association of the Deaf
ASHA	American Speech- Language- Hearing Association	NCDHH	Nebraska Commission for the Deaf and Hard of Hearing
BTNRH	Boys Town National Research Hospital	NCHAM	National Center for Hearing Assessment and Management
CDC	Center for Disease Control	NICHQ	National Initiative for Children's Healthcare Quality
CMV	Cytomegalovirus infection	NICU	Neonatal Intensive Care Unit
CSHCN	Children with Special Health Care Needs	NIH	National Institutes of Health
DHHS	Department of Health and Human Services (Nebraska)	NNSP	Nebraska Newborn Screening Program
ECHO	Early Childhood Hearing Outreach	NSLHA	Nebraska Speech Language Hearing Association
EDN	Early Development Network	OAE	Otoacoustic emissions
EHDI	Early Hearing Detection and Intervention Program	PAT	Parents as Teachers
EI	Early Intervention	PCHL	Permanent Congenital Hearing Loss
ERS- II	Vital Records Electronic Registration System (Netsmart)	PCP	Primary Care Provider (Physician)
GBYS- NE	Guide By Your Side Program	PDSA	Plan- Do- Study- Act
H&V- NE	Nebraska Hands and Voices	PHCP	Primary Health Care Provider
HIPAA	Health Insurance Portability and Accountability Act	PTI- NE	Parent Training and Information- Nebraska
HRSA	Health Resources and Services Administration	RPSDHH	Regional Programs for Students who are Deaf or Hard of Hearing
HS/EHS	Head Start/Early Head Start	SPED	Special Education and Communications Disorders
IFSP	Individual Family Service Plan	TFKF	Together for Kids and Families
JCIH	Joint Committee on Infant Hearing	TIPS	Tracking Infants Progress Statewide
MCHB	Maternal and Child Health Bureau	UNL	University of Nebraska- Lincoln

Local Resources

Omaha & Lincoln Area Resources

ACRONYM	NAME OF ORGANIZATION	CONTACT INFORMATION
Amplify	Amplify Lincoln	www.facebook.com/ AmplifyLincoln
HDAAS	Heartland Deaf Abuse Advocacy Services	www.facebook.com/ heartlanddeaf
HLAA- OA	Hearing Loss Association of America Omaha Area	Beth Ellsworth – Ellsworth.beth@cox.net Verla Hamilton – verlahamilton@cox.net Marian Reyburn – reyburnhm@cox.net
LAD	Lincoln Association of the Deaf	www.facebook.com/Lincoln- Association- of- the- Deaf
MAAD	Midwest Athletic Association of the Deaf, Inc.	www.maad.org
MRP	Metro Regional Program	www.nebraskamrp.com www.facebook.com/ NebraskaMRP
NE/IA Jr NAD	Nebraska/Iowa Jr National Association of the Deaf	www.facebook.com/Jr- NAD - Nebraska- and- Iowa
NDHMCC	Nebraska Deaf Heritage Museum and Cultural Center - Omaha	Daniel Darnall ddarnall1@hotmail.com
NSDAA	Nebraska School for the Deaf Alumni Association	www.facebook.com/ Nebraska- School- for- the- Deaf- Alumni- Association
OAD	Omaha Association of the Deaf	www.facebook.com/Omaha- Association- of- the- Deaf
SNRP	Southeast Nebraska Regional Program (Lincoln & surrounding area)	http://snrp.lps.org

Statewide Resources

Nebraska Resources (con't)

ACRONYM	NAME OF ORGANIZATION	WEBSITE	PHONE NUMBER/ EMAIL
Amplify	Amplify Lincoln	www.facebook.com/ AmplifyLincoln	402- 469- 4894 missystithem@ yahoo.com
Answers 4Families	Answers4Families	http://answers4families.org	800- 746- 8420
CWP	Central/Western Partnership (Regional Program)	http://cwp.esu9.org	402- 463- 5611
DHHS	Nebraska Department of Health and Human Services	www.dhhs.ne.gov	402- 471- 3121
EDN	Nebraska Early Development Network	http://edn.ne.gov	402- 471- 2447 amy.bunnell@ nebraska.gov
HearU	HearU Nebraska	http://cehs.unl.edu/secd/nebraska- hearing- aid- banks	402- 472- 2075 402- 472- 0043 sray2@unl.edu
IFSPweb	Nebraska's Individualized Family Service Plan	www.ifspweb.org	800- 384- 8520
MHCP	Medically Handicapped Children's Program- SSI- DCP Supplemental Security Income- Disabled Children's Program	http://dhhs.ne.gov/Pages/ hcs_programs_mhcp.aspx	800- 358- 8802
MRP	Metro Regional Program (Omaha area)	www.nebraskamrp.com	402- 339- 2090 diane_meyer@ ralstonschools.org
NE AAP	Nebraska Chapter of American Academy of Pediatrics	www.nebraska- aap.org	402- 740- 4906 info@nebraska- aap.org
NeAD	Nebraska Association of the Deaf	www.nead1902.org; www.facebook.com/ groups/441167219316137/	jonathan.scherling@ gmail.com
ChildFind NE	Nebraska ChildFind	www.childfind.ne.gov	888- 806- 6287 steve.miller @nebraska.gov
NCDHH	Nebraska Commission for the Deaf and Hard of Hearing	www.ncdhh.ne.gov; www.facebook.com/ nebraskacommissionforthedeafandhardofhearing	800- 545- 6244 ncdhh@ nebraska.gov

Statewide Resources

Nebraska Resources

ACRONYM	NAME OF ORGANIZATION	WEBSITE	PHONE NUMBER/ EMAIL
NDE	Nebraska Department of Education	http://www.education.ne.gov/	402- 471- 2295
NE- EHDI	Nebraska Early Hearing Detection and Intervention Program	http://dhhs.ne.gov/publichealth/EHDI	888- 545- 0935 DHHS.NEEHDI@nebraska.gov
NE GBYS	Nebraska Guide By Your Side	https://www.facebook.com/groups/1490212921267336/	GBYS@handsandvoicesne.org
NE H&V	Nebraska Hands & Voices	www.handsandvoicesne.org; www.facebook.com/groups/handsandvoicesne/	questions@handsandvoicesne.org
NE Moms of D/HOH Kids	NE Moms of Deaf and Hard- of- Hearing Kids	www.facebook.com/groups/293799487391503/	lutherabc5@cox.net
NERP	Northeast Nebraska Regional Program (Norfolk area)	https://sites.google.com/site/nerpne	402- 644- 2507 402- 649- 7635 jillhoffart@npsne.org
NRRS	Nebraska Resource and Referral System	http://nrrs.ne.gov	402- 472- 9815 clewis@nrrs.ne.gov
NSLHA	Nebraska Speech- Language- Hearing Association	www.nslha.org	402- 476- 9573
PTI NE	Parent Training and Information Nebraska	www.pti- nebraska.org	800- 284- 8520 info@pti-nebraska.org
RPSDHH	Regional Programs for Students who are Deaf or Hard of Hearing	http://nrpdhh.esu9.org	402- 463- 4566 rhonda.fleischer@esu9.us
SNRP	Southeast Nebraska Regional Program	http://snrp.lps.org	402- 436- 1864 jbird@lps.org

National Resources

ACRONYM	NAME OF ORGANIZATION	WEBSITE
AAP	American Academy of Pediatrics	www.aap.org
ASCD	American Society for Deaf Children	www.deafchildren.org
ASHA	American Speech- Language- Hearing Association; (Funding assistance for Audiology Services)	www.asha.org
ASLU	ASL University (American Sign Language website)	www.lifeprint.com/asl101
BTNRH	Boys Town National Research Hospital	www.boystownhospital.org
CDC	Center for Disease Control	www.cdc.gov
DHHS	United States Department of Health and Human Services	www.hhs.gov
EHDI	Early Hearing Detection and Intervention Program	cdc.gov/ncbddd/hearingloss/ehdi-programs.html
EHDI- PALS	EHDI – Pediatric Audiology Links to Services	www.ehdi- pals.org
GBYS	Guide By Your Side	www.handsandvoices.org/services/guide.html
H&V	Hands & Voices	www.handsandvoices.org
HRSA	Health Resources and Services Administration	www.hrsa.gov
HLAA	Hearing Loss Association of America	www.hearingloss.org
HS	National Head Start Association	www.nhsa.org
JTC	John Tracy Clinic Correspondence Courses (for parents of deaf or hard of hearing children)	www.jtc.org
LAURENT CLERC	Laurent Clerc National Deaf Education Center	www.clerccenter.gallaudet.edu/infotogo
MCHB	Maternal and Child Health Bureau	www.mchb.hrsa.gov
NAD	National Association of the Deaf	www.nad.org
NCHAM	National Center for Hearing Assessment and Management	www.infanthearing.org
NCSA	National Cued Speech Association	www.cuedspeech.org
NICHCY	National Dissemination Center for Children with Disabilities	www.nichcy.org
NECTAC	National Early Childhood Technical Assistance Center	www.nectac.org
NICHQ	National Institute for Children's Healthcare Quality	www.nichq.org
NIDCD	National Institute on Deafness and Other Communicative Disorders	www.nidcd.hih.gov
PAT	Parents As Teachers	www.parentsasteachers.org

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